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Title: Parents' experiences of having an excessively crying baby and implications for enhancing support services

Introduction

During their first four months, approximately 20% of infants cry for long periods for no apparent reason (Alvarez, 2004; St James-Roberts & Halil, 1991). Traditionally, this has been attributed to gastro-intestinal disorders and referred to as 'infant colic' (Illingworth, 1954; Wessel et al, 1954), but more recent evidence suggests most of these infants are healthy and go on to develop normally (Lehtonen, 2001; Stifter & Braungart, 1992). The crying, which tends to peak at around 1-2 months of age (Barr, 1990; St James-Roberts & Halil, 1991), usually resolves spontaneously by five months and is now thought to be linked to normal development (Barr & Gunnar, 2000; Barr et al, 2005; St James-Roberts et al, 2013).

Whilst much research has focused on the causes of excessive infant crying, there is growing recognition of the need to understand its impact on parental well-being. The crying, and in particular the 'unsoothable' crying bouts often associated with it (Fujiwara et al, 2011), cause considerable alarm and distress to parents. The impact of the crying also depends partly on parents' coping abilities. Factors such as depression and anxiety and influence how parents interpret and respond to infant crying, whilst social isolation may also increase its impact (Laurent & Ablow, 2012; Pearson et al, 2010). As a result, the actual duration of the crying may not be as significant in determining its impact as parents' subjective experience of it. In this context, the term "excessive crying" is used to indicate crying judged by parents to be 'too much', rather than an objective measure of its duration.

Excessive crying has also been found to impact on a range of outcomes for both parent and infant, including premature termination of breastfeeding (Howard et al, 2006), over-feeding (Stifter et al, 2011), parental distress, anxiety and depression (Kurth et al, 2011; Murray & Cooper, 2001; Stifter et al, 2003), poor parent-child relationships (Kurth et al, 2011; Oldbury & Adams, 2015; Tabuchi & Shimada, 2008), problems with long-term child development (Wolke et al, 2002) and, in a small number of cases, infant abuse (Barr et al, 2006; Fairbrother et al, 2015).

In other studies, parents reported feeling unprepared, challenging their expectations of parenthood and leading to feelings of disappointment, both in themselves and their baby (Cox & Roos, 2008; Ellett et al, 2009; Megel et al, 2011; Nash et al, 2008). The perceived stigma and shame of the excessive crying led to self-imposed isolation, reducing support and external contact (Ellett & Swenson, 2005; Megel et al, 2011). Parents described the crying as overwhelming and frustrating, evoking anger and resentment (Gaffney et al, 2008; Landgren & Hallström, 2010), sometimes including thoughts of aggression towards their baby (Fairbrother et al, 2015; Levitsky & Cooper, 2000).

Despite these negative outcomes and experiences, there are currently no evidence-based services in the UK to support parents with an excessively crying baby. As a result, parents consult books, magazines or websites, which often provide conflicting advice (Catherine et al, 2008). They also seek help from health professionals, but as only around 5% of such infants are found to be unwell (Freedman et al, 2009), this represents a significant potentially avoidable cost to health services (Morris et al, 2001). The “Surviving Crying” study (Long et al, 2018) represented a first step towards developing and evaluating an intervention to support parents worried about their baby’s excessive crying. To inform the development of the intervention, the first

stage of the study aimed to verify and provide a more detailed understanding of existing qualitative findings within a UK health service context. To achieve this, focus groups were held to consult with parents with recent experience of an excessively crying baby. This paper reports the findings from these focus groups and the implications for practice.

Methods

Aim

To explore the experiences of UK parents with a baby who had previously cried excessively, and to obtain their views on what support they would have wanted.

Design

This was the qualitative aspect of the development phase of a larger mixed methods feasibility study (Long et al, 2018).

Ethical approval

Study public registration no.ISRCTN84975637; ethical approval provided by De Montfort University (13450) and the National Research Ethics Committee East Midlands (Nottingham) (project ID 152836; NRES: 14/EM/1202).

Recruitment

Parents who had previously had an excessively crying baby were identified by Health Visitors/Community Public Health Nurses (HV/CPHNs) using the following criteria:

- The crying had taken place in the first 6 months and was now resolved;
- The baby had no underlying health problems at the time of the crying;

- Parents were English speaking, or supported by an English speaker.

HV/CPHNs obtained consent from the parents for a researcher to contact them. The study was also publicised through the National Childbirth Trust and in local community settings, enabling parents to contact the research team directly. On receipt of an expression of interest, the researchers telephoned parents to explain the study and confirm eligibility. Eligible parents were sent a letter and information sheet and then followed up to confirm their interest and availability. To facilitate participation, parents were able to bring their babies and/or older children. In order to obtain a diversity of views within the time constraints of the study, a sample size of 20 was set.

Data Collection

Data were collected between April-August 2015, using a semi-structured format to guide discussion. Having obtained written consent, parents were asked open-ended questions about their experiences of having an excessively crying baby: what they found challenging; what had helped them to manage; family, community and health service support; and what resources should be provided as part of routine NHS care.

Whilst the initial intention was to collect all data through focus groups, on a number of occasions only one parent attended for the focus group and in these instances an interview was conducted using the same format. Groups were facilitated by two researchers, whilst two others wrote observations and provided informal childcare when needed. Roles were shared between two researchers for interviews. All parents received shopping vouchers in acknowledgement of their participation.

Four focus groups of 2 - 5 parents and six individual interviews were held, a total of ten events. Sessions were audio-recorded for later verbatim transcription and anonymisation.

Data Analysis

Thematic analysis was used to analyse the data (Braun & Clarke, 2014) supported by NVivo10 software (International Pty Ltd, 2012). One researcher conducted a brief preliminary analysis of the transcripts to produce a summary of key themes, which was agreed by the team. A second researcher then undertook a full analysis, reading all transcripts several times and conducting a line-by-line analysis of the content. Data were initially coded to a large number of themes, which were refined by grouping similar themes under broader headings. These themes were shared with the research team and, following discussion, refined and agreed.

The findings informed the development of the intervention resources, and the draft resources were shared with parents and HV/CPHNs to ensure the team had accurately understood parents' needs and the current context of healthcare provision.

Results

Eighteen mothers and two fathers (both partners of participating mothers) took part (Table 1 gives demographic details). Most participants were white British, with high education levels, and married or living with a partner. Nearly half of the babies were second or third-born, with eight of the 18 families having other children who had not cried excessively. Only one parent had experienced two excessively crying babies.

Three key themes were identified: Disrupted expectations and experiences of parenthood; Stigma and social isolation; and Seeking support and validation of experience.

1. Disrupted Expectations and Experiences of Parenthood

Participants reflected that prior to their baby's birth, their expectations were positive, with the majority having little or no awareness of the phenomenon of excessive crying. They were therefore shocked and unprepared for the experience.

I think the, the expectation that you have after you have been carrying your unborn child and then feeling this is going to be wonderful, and the screaming just doesn't stop, and you think to yourself "it's going to stop, it will just be the first week" and it didn't for a long, long time. (P1P19)

Parents tried many strategies to comfort their babies but these often had no effect. Their inability to soothe their babies frequently produced feelings of inadequacy, frustration and anxiety, and eroded their confidence in their parenting ability:

I would say it made you feel like you are no good at it [being a parent], like you are helpless really, because you try everything. I expected when you have a baby that when you pick them up and you comfort them they are going to stop crying. But when she carried on crying you try and feed them, you change them, there is nothing wrong with them you just feel like useless. (P1P7)

Whilst some experiences were linked to being a new parent, participants who already had other children also experienced shock and disrupted expectations. They recounted being taken aback by the difference from their previous experiences (even

in one instance where their previous baby had cried excessively), and how this undermined their belief in their skills as a parent.

Because this is, he's my third and the other two haven't been like it, people think "oh well you should, you know, you know what you are doing", but when they are totally different you feel at a bit of a loss. (P1P14)

Managing their baby's crying also often resulted in parents being physically exhausted, and when the crying continued at night, sleep deprivation further undermined their ability to cope. Even basic self-care could be compromised:

I wasn't looking after myself, I wanted to but I just couldn't because, everything was so consumed with the crying that I just didn't, I just almost neglected myself. (P1P13)

The experience of managing the crying also created tensions in relationships sometimes, particularly at night when parents were most tired. During the day, many mothers were alone at home with their baby and some felt that the strain of this situation was not fully understood or acknowledged by their partner, creating friction between the couple:

I don't think he really understood what it was like to be at home all day on your own with a crying baby. And whilst he never came home and said "well it's a mess, where is my dinner?" you still have to do those things. He'd come in and be, "oh I am so tired, I have been at work", and expect to have a chill out and she would be there screaming the place down. I started to resent him. (P1P16)

In contrast, others described examples of a positive shared parental approach:

He would do the night feeds and then I would get up at 6. With the crying to be fair he never lost his temper once, he didn't shout. In the middle of the night he would wake up and say "oh give her to me". And he slept downstairs for three months with her so that I got sleep. (P1P5)

2. Stigma and Social Isolation

Even where parents were managing to work together to cope with the excessive crying, its unexpected nature and other people's reactions posed significant challenges. Parents perceived that both they and their baby were somehow different from others who appeared to have a 'normal baby'.

"The year I had my baby there were five of us that all went to school that all had our babies within a few months. All of their babies were happy, they never particularly cried. So we were very much the odd ones out". (P1P16).

Negative comparisons between their situation and that of others often created a sense of isolation and loneliness. Whilst parents recognised that meeting friends or attending groups could be beneficial, the all-consuming task of trying to soothe their baby, combined with physical exhaustion, made going out both physically and mentally challenging. Furthermore, sometimes their sense of isolation and not being "normal" was only compounded by these experiences:

"I went to them baby massage classes but I only went for one...because he was crying the whole time we were there. I couldn't do a lot with him because I just thought it's just gonna be embarrassing. Especially cos' you'd have all the mums there and they'd be like "oh my baby is like so", "he's brilliant, sleeps 8 hours, happy to just sit there", but that don't make you feel better." (P1P17)

Discussing their crying baby at parent and baby groups was seen as taboo, as was admitting to peers that they were finding the experience of parenthood difficult and struggling to cope:

It's not the kind of thing where you come to a baby group ...and you say "do you know what, I have got a really troublesome baby". You just don't because you are conditioned to think I have got to go and talk about how lovely my baby is. (P1P3)

More generally, when parents did take their babies out, they often experienced intolerance and criticism from others, which reinforced their perceptions of being inadequate parents, further undermining their confidence:

And you always get people who think they are doing good by coming up and "oh what's the matter with her?" and actually it just makes you feel worse as a parent. (P1P6)

I remember going in (supermarket) with her and she was absolutely screaming... and this old lady said to me, "why can't you just shut your baby up, do they have to cry all the way round the shop?" (P1P5)

Feelings of failure and inadequacy affected parents' willingness to seek support, even in some cases from partners or close family:

It's sort of like admitting defeat isn't it....you feel like you have been defeated by this little child and it's actually admitting that to your family. Even my other half I never told him how bad I actually felt. (P1P5).

Parents' reluctance to ask for help was also associated with not wanting to "*inflict [baby] on other people*" (P1P1) and this hesitancy was sometimes confirmed when friends and family were unwilling to help or avoided visiting because of the crying:

Nobody would even babysit for me or anything either. My mum couldn't cope with her because she didn't sleep. My mum would just say "I can't do it". We never ever got a break because nobody could deal with her because she was so hard. (P1P5)

Notably, for some, a reluctance to seek help was fuelled by fears of being judged by others, particularly health professionals, who they feared would take their baby away.

"But you do think that don't you? "Oh my god they (health professionals) are going to come round and take her off me". (P1P1)

3. Seeking Support and Validation of Experience

Feelings of inadequacy and difference also impacted more widely on parents' help-seeking experiences and interactions with health professionals. Parents described repeatedly going through mental checklists of routine causes of crying such as nappy changing, feeding and temperature. When they had exhausted these options, they became concerned their baby was unwell. Many reported repeated internet searching, particularly of professionally endorsed websites, to find other explanations for the excessive crying, but struggling to find specific information:

"Yeah, (I used the internet)a lot, when I was trying to look on Google, some stuff came up but it wasn't stuff that gave you proper advice or anything on what to do." (P1P10)

In addition to reliable factual information, online peer support was appreciated by some, particularly given the difficulties experienced in trying to go out. Parent forums offered important validation and reassurance as they discovered they were not the only ones dealing with an excessively crying baby.

“I was just looking for what other people had been through and what they’d said; the whole act of finding and reading what other parents have been through helped me - I felt like I wasn’t on my own.” (P1P18)

Whilst online information and peer support provided some help, for most parents this was not sufficient to allay their concerns. Despite their reluctance, they therefore sought advice and reassurance from health professionals, particularly doctors and HV/CPHNs, and described experiencing a wide range of responses.

In most cases no physical cause for the crying was found, but as it continued, many parents returned repeatedly to health professionals, becoming convinced that there was something seriously wrong:

“It (crying) went on and on for two weeks straight it was, he just cried so much. I remember going to the doctors’ and then the midwife was coming round and I asked, “what’s he crying for?”, And I just kept looking at him and thought “what’s wrong with him?”, why is he crying?”. (P1P12)

A few parents felt their concerns were not taken seriously by health professionals or that they were considered to be exaggerating, which increased their frustration and distress.

“You are banging your head against a brick wall, you are knocking on everyone’s door and you are not getting anywhere. So not only did I feel

undervalued from a mother's point of view [and] feel that what I was doing was wrong, but as an individual, as an adult I felt like nobody was listening to me, nobody cared, nobody is taking me seriously, it was a nightmare."

(P1P11)

In other instances, health professionals were supportive, but parents questioned their knowledge and skills in relation to excessive crying:

"I found that the health visitor was helpful, she was quite sympathetic. She didn't have the answers that I felt that I needed, and she didn't have probably the experience of babies that cry. But it just made it just nicer to talk to somebody who was sympathetic to talk to. (P1P8)

or found that the support offered did not fully meet their needs or expectations:

"I used to think she (health visitor) should come to my house and see what I am going through. She never came to my house, she'd ring me and she was just trying to tell me things to do over the phone." (P1P7).

For a few parents, lack of continuity of support was an additional difficulty, and the need to repeatedly explain their situation made them less likely to share their anxieties:

"It's a lot of work, because we have had so many health visitors it's like starting from scratch all over again. He has three already, he's only 15 months old and not one of them knows him. So when they ring I just say "yes I am fine". I just don't bother now." (P1P5)

Other parents described examples of highly supportive care. Home visits from HV/PCHNs were particularly valued, allowing a health professional to see the crying

at first-hand, and in doing so validating parents experience. Continuity of care was also seen as important, enabling the development of a much-valued relationship:

I knew you were only meant to see them (health visitors) routinely at 6 weeks, so for her to offer to come back the next week, I took that as, "oh that's really nice, like really", so when she came back the second week it was lovely, she'd come, she'd come to see how I was. (P1P1)

"My health visitor was really supportive, even now she's really supportive. She was really nice, really good, even like now she is really good, and she always like rings me to see how I am. She has given me her number and said if you ever feel down, if you ever want to talk to anyone ring me and, I go to the groups and she is there sometimes and she has a chat and she is really helpful. "(P1P9)

Discussion

Participants' accounts clearly described how having an excessively crying baby had presented significant emotional and physical challenges. Whilst the crying had now resolved, in some cases more than a year previously, many parents still became distressed recalling the difficulties they had faced. The excessive crying had shattered their preconceptions of parenting a new baby and, because it was not a phenomenon they were previously aware of, led them to question whether there was something wrong. When no medical problem could be identified, many parents felt a sense of personal inadequacy and failure, leading them to withdraw from social contact and be reluctant to seek help. The focus group findings concur with other studies (Landgren & Hallström, 2010; Megel et al, 2011), where parents attempted to maintain a façade of having the 'perfect baby' by removing themselves from public

scrutiny. Lack of understanding and support from others, including health professionals in some instances, increased their distress and isolation.

Stigma theory (Goffman, 1990) provides an insight into the behaviour of those who perceive themselves, or are perceived by others, not to fulfil the characteristics associated with socially constructed identity categories. Whether consciously or not, individuals are usually very aware of the expectations of society, and of how others might perceive them as failing to make “the standard”, resulting in feelings of shame and low esteem (Goffman, 1990). In relation to parenting, there are expectations that it should be done ‘well’ and without undue distress or difficulty (Maushart, 1997; Phoenix et al, 1991). Such notions are reinforced by widespread media representations of smiling parents with perfectly behaved infants (Kaplan, 1993). However, as was evident for the participants, these expectations of parenthood frequently meet reality with significant dissonance (Belsky et al, 1986; Guendouzi, 2005; Lawrence et al, 2007). Goffman (Goffman, 1990) suggests that when there is doubt as to whether individuals fulfil the socially required characteristics, or they possess an attribute that makes them different from others, this lack or attribute is regarded as a stigma and can have a discrediting effect, being seen as a shortcoming or failing, with individuals being viewed as different or ‘other’. These experiences were evident in participants’ perceptions of themselves and their babies as ‘different’, with these feelings being reinforced by other people’s reactions. Their perceptions of themselves being inadequate parents lead them to be reluctant to seek help or admit they were not coping as they felt they should be.

Implications for practice

This study has highlighted how unprepared parents were for having an excessively

crying baby and how prior knowledge would have helped them cope. Concerns about 'doing something wrong' or being a 'bad parent' resulted in an initial reluctance to seek help which was often only overcome as the crying continued. These are important considerations for health professionals supporting parents in the antenatal and immediate postnatal period. Parents need timely, accessible and evidence-based information about excessive infant crying, acknowledgement of the challenges of managing the crying, and reassurance that finding it difficult is not an indicator of poor parenting.

Other research into initiatives to reduce perceived health-related stigma has identified the importance of education and counselling in raising awareness and modifying behavioural and cognitive responses to experiences (Heijnders & Van der Meij, 2006). However, because stigma is socially constructed (Corrigan, 2005), interventions need to be aimed not only at those directly affected, but also the wider population (Heijnders & Van der Meij, 2006). Increasing awareness of excessive crying and its impact could therefore enable health professionals to support parents more effectively, increase public tolerance, and help prospective parents re-fashion their expectations, reducing feelings of inadequacy. Consideration also needs to be given to offering internet-based group support, as this can allow individuals experiencing stigma to interact with others in a relatively anonymous fashion, providing a way to belong which may not otherwise be available (Parker Oliver et al, 2017).

Some parents reported disappointment at the level of care and support received from health professionals. The schedule of HV/CPHN contacts reported in this study was generally reflective of the universal service delivery of the Healthy Child Programme (DOH, 2009; 2011; PHE, 2016), including an antenatal home visit, new

birth visit and further contact at 6 weeks and 4 months. Specific enhanced care packages can be offered, including support for unsettled infants, but this study indicates the need for a more specialised package to support parents with excessively crying babies. Specific recommendations are listed in Table 2.

Limitations

Participants were mostly white middle class educated women supported by a partner, and future research needs to explore the perspectives of fathers, ethnic minorities, single parents, and vulnerable and disadvantaged families.

During the time when focus group participants had their excessively crying baby, substantial organisational changes to the NHS HV/CPHN services were being undertaken which may have influenced experiences of health visiting services, including disruptions to the continuity of provision.

CONCLUSION

Parents reported that having an excessively crying baby was an unexpected and distressing experience that undermined their confidence in their parenting skills and led them to isolate themselves. Participants felt that more information before or soon after their baby's birth might have helped them to cope better. Understanding the experience of excessive crying and the perceived stigma associated with it can enable development of better support for parents, including the education and training of health professionals that care for them. The findings highlight a currently unmet need in the National Health Service.

Key points

- Parents were unprepared for and distressed by their baby's excessive crying

- Feelings of failure made parents reluctant to disclose concerns and seek help
- Some experienced a lack of understanding from health professionals and general public
- Specific resources and services are needed to help parents cope with excessively crying babies
- Greater public awareness of excessive crying could increase tolerance and support

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